

Quality of life of children with idiopathic nephrotic syndrome according to clinical types

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Abstract:

Idiopathic nephrotic syndrome (INS) is a major manifestation of chronic idiopathic glomerulonephritis and a common disease in children. The cause and pathogenesis of the disease have not been clarified so far. The treatment is usually a long-term process, from a few months to several years, even decades, including the period of hospitalisation, outpatient treatment period and follow-up period after treatment. The INS patients are negatively affected by the disease and its treatment process. The aim of this study is to assess the health-related quality of life (QOL) of children with INS according to clinical types in Haiphong Children's Hospital. **Object:** Describe some factors related to the QOL of children with INS. **Subjects:** 71 patients diagnosed with INS, who are being monitored and treated at Haiphong Children's Hospital from 10/2015 to 05/2016. **Methods:** Prospective studies, descriptive cross-sectional. QOL of the patients is assessed by the PedsQL 4.0 scale; the higher score shows that the lower QOL. **Results:** The general QOL score of children with INS (21.24 ± 13.91) was higher than normal children (16.98 ± 10.20). Children with steroid-resistant INS have a higher score (31.62 ± 14.32) than children with steroid-dependent (20.57 ± 9.08) and responsive INS (14.58 ± 6.83). The QOL score of children with one of the symptoms Cushing's face, hirsutism or acne are significantly higher than children without the corresponding symptoms. Children who finished their treatment had a lower score (15.47 ± 7.42) than children being treated (21.33 ± 10.23). The average QOL score has a linear correlation with the duration of INS. **Conclusion:** The general QOL of children with INS substantially declined compared with that of healthy children. The QOL of children with steroid-dependent and resistant INS is lower than that of the children with steroid-responsive type. The QOL of children with one of the symptoms Cushing's face, hirsutism or acne is significantly lower than that of children without the corresponding symptoms. The QOL of children who completed treatment is higher than the group being treated. The longer the duration of treatment, the more the children's QOL declined.

Keywords: children, idiopathic nephrotic syndrome, quality of life.

Classification number: 3.2

Background

INS is a major manifestation of chronic idiopathic glomerulonephritis. The disease has a long duration, often recurs, needs long-term treatments and has many complications in itself and in the treatment processes [1, 2]. It negatively affects patients in terms of health, emotion and family economic condition, and hence, causes a negative impact on the QOL of the patients. So far, there are only a few studies on the QOL of children with chronic diseases in Vietnam, and there is no study on the QOL of children with INS in Haiphong [3]. Hence, how is the QOL of children with INS like? What are the factors relating to the QOL of children with INS? Those are the questions that need answers. Therefore, we conducted this study to: 1) Assess the health-related QOL of children with INS in Haiphong Children's Hospital, 2) Describe some of the factors related to the QOL of children with INS. Hopefully, the results will contribute to the treatment and improve the QOL of children with INS, which is a common disease in children in Vietnam.

Subjects and methods

Research subjects

71 patients with INS were monitored and treated at Haiphong Children's Hospital from 10/2015 to 05/2016.

The diagnostic criteria of INS according to ISKDC (International study of kidney diseases in children) are: edema, proteinuria ≥ 50 mg/kg/24 hours, serum protein decrease (≤ 56 g/l), serum albumin decrease (≤ 25 g/l) and serum cholesterol increase (≥ 5.5 mmol/l).

Classification of nephrotic syndrome according to responsiveness to steroid treatment:

- Steroid-responsive: after using continually, initial treatment is conducted with prednisone 2 mg/kg/day in 4 weeks. If the patient is in remission, it means negative or trace proteinuria.
- Steroid-dependent: the patients had 2 continuous relapse during the treatment or relapse occurred within 14 days after stopping medication.

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- Steroid-resistant: after using continually, initial treatment is conducted with prednisone 2 mg/kg/day in 4 weeks, the patients had no relief (positive proteinuria >50 mg/kg/day).

Patients with secondary nephrotic syndrome triggered after systemic lupus erythematosus, Henoch - Schonlein purpura, diabetes were excluded.

A control group data from the study of Nguyen Thi Thanh Mai, et al. [4] is used, which includes 74 healthy children in the same conditions of research group.

Research methodology

Study design: prospective studies, descriptive cross-sectional.

Each patient completed a designed medical record form, which includes information about age, gender, family circumstances, habitat geography, learning results, information about the disease such as duration, classification, treatment status and appearance symptoms. Besides, the QOL of patients are assessed by direct interviews using the scale PedsQL 4.0 of Pediatric Hospital and Health Center Sandiego, California. The PedsQL 4.0 scale is the result of research and development projects about the QOL assessment tools in the 15 years of the authors Varni, et al., that was published in 2002 [5]. This scale consists of 23 questions in four areas: health and physical activity, emotional, social friendships, learning at school and the given points based on the level of problems affecting children within 1 month before the evaluation: 0 point if it is never a problem, 1 point if it is almost never a problem, 2 points if it is sometimes a problem, 3 points if it is often a problem, 4 points if it is almost always a problem. The assessment of health problems and children’s activities is out of a total points of 23, as explained above. The higher total score shows the higher difficulty levels, which means that the general QOL is lower.

Data is processed by the software SPSS 20.0.

The research was permitted and approved by the Council of Ethics in biomedical research of Haiphong University of Medicine and Pharmacy. The participation of the subjects in the study is voluntary. The information of the patients is confidential and only serve scientific research.

Results

General characteristics of the study subjects

The patients’ age is from 6 to 18 years, and the average age is 11.2±3.38. 62% of them are primary school students. There are 57 males, 14 females, and the proportion of male to female is 4/1. 33.8% of the patients are from urban areas and the rest are from rural areas. The percentage of patients with onset INS is 23.9% and of recurrent type is 76.1%. The

percentage of patients with steroid-responsive INS is 74.6%, steroid-dependent and steroid-resistant types are both 12.7%. 78.9% patients are in treatment process and 21.1% of them have finished treatment.

QOL of children with INS (Tables 1, 2)

Table 1. Average QOL score of children with INS and healthy children.

Fields	Average PedsQL score of children with INS (n=71) (X̄±SD)	Average PedsQL score of healthy children [4] (n=74) (X̄±SD)	P
Physical health	7.55±5.96	5.03±3.91	<0.05
Emotion	5.72±3.45	4.85±3.12	<0.05
Social life	4.73±2.81	2.55±2.40	<0.05
Learning	6.24±3.52	4.51±3.01	<0.05
General QOL	21.24±13.91	16.98±10.20	<0.05

Comment:

- The highest score belongs to the physical field.
- The score of the children with INS is significantly higher than that of the healthy children, which means that the QOL of the patients is lower.

Table 2. The average QOL score of children with INS regarding disease classification and treatment status.

	n	Average PedsQL score (X̄±SD)	P
Classify by development	Onset	17 14.85±7.17	>0.05
	Recurrent	54 18.31±8.93	
Classify by response to steroid treatment	Responsive	53 14.58±6.83	<0.05
	Dependent	9 20.57±9.08	
	Resistant	9 31.62±14.32	
Continuing treatment	56	21.33±10.23	<0.05
Finished treatment	15	15.47±7.42	

Comment:

- The average QOL score of children with steroid-resistant nephrotic syndrome is the highest and the steroid-responsive group has the lowest score with a statistical difference.
- The children being treated have a higher average QOL score than the children who finished treatment with a statistical difference, which means that the QOL of children being treated is lower than the finished group.

Some factors related to the QOL of children with INS (Tables 3, 4; Fig. 1)

Table 3. The average QOL score and appearance characteristics.

Appearance characteristics		n	PedsQL score ($\bar{X}\pm SD$)	p
Cushing's face	Yes	38	21.37±10.14	<0.05
	No	33	12.81±5.46	
Hirsutism	Yes	39	22.13±11.23	<0.01
	No	32	11.57±6.58	
Acne	Yes	24	23.08±10.19	<0.05
	No	47	13.93±7.41	
Genital edema	Yes	30	18.03±10.12	>0.05
	No	41	16.16±9.56	

Comment: the PedsQL scores of children with one of the symptoms Cushing's face, hirsutism or acne are significantly higher, and the QOL is lower than that of children without the corresponding symptoms.

Table 4. The average QOL score in relation to types of INS and the learning outcomes of INS children.

Learning outcomes	Average PedsQL score ($\bar{X}\pm SD$)			p
	Steroid-responsive INS (n=53)	Steroid-dependent INS (n=9)	Steroid-resistant INS (n=9)	
Excellent (n=30)	11.90±6.14	25.30±7.07	None	<0.05
Good (n=33)	16.25±8.90	22.33±8.08	31.20±10.05	<0.05
Medium (n=8)	17.20±8.27	24.45±9.90	43.40±15.30	<0.05

Comment:

- There are no children with steroid-resistant INS who achieve excellent academic result. Among children with excellent academic result, the average PedsQL score in children with steroid-dependent INS is higher than that of the children with steroid-responsive INS with a statistical difference.

- Among children with good and medium results, the PedsQL score of children with steroid-resistant INS is the highest, followed by that of steroid-dependent INS group and then, steroid-responsive INS group with a statistical difference.

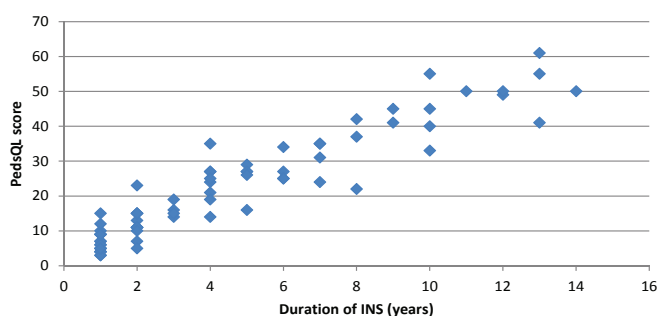


Fig. 1. Average PedsQL score and the disease duration.

Comment: the average QOL score has a linear correlation with the duration of INS, according to the equation $y = 1.9 + 4.7x$ (y is the PedsQL score, x is the duration of INS), with $r = 0.56, p < 0.05$.

Discussion

QOL of children with INS

- The average QOL score in the fields of children with INS increases. Compared with the children with nephrotic syndrome in the study of D.T.T. Binh [3] who were interviewed with the same scale of PedsQL, our team's scores did not differ significantly. Compared with a control group of 72 healthy children in the study of N.T.T. Mai, et al. [4] who also interviewed with the scale PedsQL, the QOL score is higher. Thereby, it can be seen that the groups of children with nephrotic syndrome in our study had significantly impaired QOL.

- Type of INS: we studied it in 2 ways by dividing the patients.

+ The first is based on the development of the disease; children with nephrotic syndrome who had recurrent episodes have higher QOL score than the children in the onset of illness. Relapses are common characteristics in patients with nephrotic syndrome; the relapse rate is high, which takes prolonged treatment time and the children's QOL is affected more. The causes of relapse may be infections (respiratory, digestive), allergies or children and families who do not comply with the treatment and arbitrarily change the dose or stop using medicine.

+ The second is based on the response to steroid treatment. The average QOL score of children suffering from steroid-resistant nephrotic syndrome is the highest (31.62±14.32), followed by the steroid-dependent group (20.57±9.08). These two groups of patients have an extremely high recurrence rate or are not treatable with steroids, and thus, the treatment will be more difficult and prolonged, which means that the QOL of these children are significantly reduced for the reasons mentioned above. Moreover, the QOL of children with steroid-responsive INS also declined, similar to a study by E.M. Rütth, et al. [1].

- As for the treatment status, most patients in the study group were in the treatment process (78.9%). The rate of finished treatment is still low because the response to treatment with the drug is not an optimal or a recurrent disease. Every time, going for regular medical exams, despite discontinuation of therapy or treatment being continued, the children and family always have the psychological fear of relapse or worsening of the disease. The average QOL score in the group of children that finished treatment was significantly lower compared with the continuing treatment group. This is consistent to the study of D.T.T. Binh [3].

Some factors related to the QOL of children with nephrotic syndrome

- The QOL and the appearance symptoms: all appearance symptoms affect the QOL of children. The study results

showed that the average QOL score of children with one of the symptoms Cushing's face, hirsutism or acne was significantly higher than that of the children without the corresponding symptoms ($p < 0.05$). Specific research was conducted in the 2 fields of feelings and friendships-social relationship; children with acne have the most difficulty with highest emotion score and the highest social score. The symptoms often lead the children to lose confidence when communicating with friends, teachers and the people around them, making them not want to attend school regularly, afraid to play with friends or even not want to leave their home. According to researches by Soliday, et al. [6] and M. Metah, et al. [7] regarding the changes in the behaviour of children with nephrotic syndrome, the proportion of children having behavioural changes is 68%, which is higher than that of the healthy group with 21.6%.

- The average QOL score in relation to the types of INS and the learning outcomes of INS children.

D.T. Selewski, et al.'s study [8] shows that QOL score in the learning field increases, which means that the QOL related to learning is declined.

In our study, no children with steroid-resistant nephrotic syndrome achieve excellent school result. The average QOL score of children with steroid-resistant type is very high, in which children who achieve good and medium result are the highest, much higher than the other groups, with $p < 0.05$. The steroid-resistant type may not only cause children to treat persistently, use a variety of drugs but also make the children and their families depressed and worried that they will not be cured. With such influences, the children will not be able to concentrate in class learning, the impact on health and the disease appearance; additionally, the treatment greatly affects a child's learning. This shows that the need to find appropriate psychological measures help this group integrate life around, adjust psychosocial better.

- The QOL and the disease duration: the average disease duration of the research team was 4.69 ± 3.78 years and the children infected for 1 to 5 years accounted for the highest proportion (40.8%). According to our research, there is a linear correlation between the QOL and the duration of treatment: the longer duration of treatment, the more declined children's QOL. The affected children within one year are often in the onset or in the steroids-sensitive group, with no recurrence, and appeared with fewer side effects, not greatly affected by emotions, social and learning of children. Children must comply with the treatment, which many do not want to, and are even more anxious about the effectiveness of treatment, or whether the disease can worsen. A study of D.M. Youssef, et al. [9] shows that INS patients encounter significant problems with anxiety, depression and anger during treatment. Besides, many other factors mentioned in the study also reduced the QOL of children. Prolonged disease duration means that the children are affected much more by the QOL.

Conclusions

1. The QOL of children with INS according to clinical types:

- The general QOL of children with INS substantially

declines compared with that of the healthy children.

- The QOL of children with steroid-dependent and resistant nephrotic syndrome is lower than that of the children with steroid-responsive type.

2. Some factors related to the QOL of children with INS:

- The QOL of children with one of the symptoms Cushing's face, hirsutism or acne is significantly lower than that of the children without the corresponding symptoms.

- The QOL of children who finished treatment is higher than that of the treating group.

- There is a linear correlation between the QOL and the duration of treatment: the longer the duration of the treatment, the more the decline in the children's QOL.

Recommendation

- Continuing study to find new INS treatment methods that are more effective and have fewer complications.

- Training and guiding children's families to detect the recurrence of the disease early in order to have timely treatment and reduce complications.

- Finishing medication when the children meet the suitable criteria.

Competing interest

The authors declare that they have no competing interests.

Authors' contribution

Authors participated in study design, protocol development and performance, data analysis, interpretation of data and writing of the manuscript, carried out the clinical data collection and data analysis and read and approved the final manuscript.

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